

Introduced by Senator Johnston

February 18, 1998

An act to amend Sections 124975 and 124980 of the Health and Safety Code, relating to hereditary disorders.

LEGISLATIVE COUNSEL'S DIGEST

SB 1800, as introduced, Johnston. Hereditary disorders.

(1) Existing law requires the Director of Health Services to establish any regulations and standards for hereditary disorders programs as the director deems necessary to promote and protect the public health and safety in accordance with certain principles.

This bill would require that the standards for hereditary disorders include approval, accreditation, certification, or licensure of personnel offering screening programs for hereditary disorders.

(2) Existing law provides that among the principles for the establishment of any regulations and standards for hereditary disorders is that counseling services for these disorders be available through the program or a referral source for all persons determined to be or who believe themselves to be at risk for a hereditary disorder when the belief arises as a result of screening programs.

This bill would require, for purposes of these regulations and standards, that pre- and post-counseling services for hereditary disorders be provided by persons with appropriate training and experience. The bill would also revise certain legislative findings and declarations relating to hereditary disorders.

Vote: majority. Appropriation: no. Fiscal committee: yes.
State-mandated local program: no.

The people of the State of California do enact as follows:

1 SECTION 1. Section 124975 of the Health and Safety
2 Code is amended to read:
3 124975. The Legislature hereby finds and declares
4 that:
5 (a) Each person in the State of California is entitled to
6 health care commensurate with his or her health care
7 needs, and to protection from inadequate health services
8 not in the person's best interests.
9 (b) Hereditary disorders, such as sickle cell anemia,
10 cystic fibrosis, and hemophilia, are often costly, tragic,
11 and sometimes deadly burdens to the health and
12 well-being of the citizens of this state.
13 (c) Detection through screening of hereditary
14 disorders can lead to the alleviation of the disability of
15 some hereditary disorders and contribute to the further
16 understanding and accumulation of medical knowledge
17 about hereditary disorders that may lead to their eventual
18 alleviation or cure.
19 (d) There are different severities of hereditary
20 disorders, that some hereditary disorders have little effect
21 on the normal functioning of individuals, and that some
22 hereditary disorders may be wholly or partially alleviated
23 through medical intervention and treatment.
24 (e) All or most persons are carriers of some deleterious
25 recessive genes that may be transmitted through the
26 hereditary process, and that the health of carriers of
27 hereditary disorders is substantially unaffected by that
28 fact.
29 (f) Carriers of ~~most~~ deleterious genes should not be
30 stigmatized and should not be discriminated against by
31 any person within the State of California.
32 (g) Specific legislation designed to alleviate the
33 problems associated with specific hereditary disorders
34 may tend to be inflexible in the face of rapidly expanding



1 medical knowledge, underscoring the need for flexible
2 approaches to coping with genetic problems.

3 (h) State policy regarding hereditary disorders should
4 be made with full public knowledge, in light of expert
5 opinion and should be constantly reviewed to consider
6 changing medical knowledge and ensure full public
7 protection.

8 (i) The extremely personal decision to bear children
9 should remain the free choice and responsibility of the
10 individual, and should not be restricted by the state.

11 (j) Participation of persons in hereditary disorders
12 programs in the State of California should be wholly
13 voluntary, except for initial screening for
14 phenylketonuria (PKU) and other genetic disorders
15 treatable through the California newborn screening
16 program. All information obtained from persons involved
17 in hereditary disorders programs in the state should be
18 held strictly confidential.

19 (k) In order to minimize the possibility for ~~the~~
20 ~~reoccurrence~~—of abuse of genetic intervention in
21 hereditary disorders ~~programs in the state~~, all ~~programs~~
22 ~~offering~~ screening programs for heredity disorders shall
23 comply with the principles established in the Hereditary
24 Disorders Act (Section 27). The Legislature finds it
25 necessary to establish a uniform statewide policy for the
26 screening for heredity disorder in the State of California.

27 SEC. 2. Section 124980 of the Health and Safety Code
28 is amended to read:

29 124980. The director shall establish any regulations
30 and standards for hereditary disorders programs as the
31 director deems necessary to promote and protect the
32 public health and safety; *Standards shall include*
33 *approval, accreditation, certification, or licensure of*
34 *personnel offering screening programs for hereditary*
35 *disorders. Regulations adopted shall be* in accordance
36 with the principles established pursuant to this section.
37 These principles shall include, but not be limited to, the
38 following:

39 (a) The public, especially communities and groups
40 particularly affected by programs on hereditary

1 disorders, should be consulted before any regulations and
2 standards are adopted by the department.

3 (b) The incidence, severity and treatment costs of
4 each hereditary disorder and its perceived burden by the
5 affected community should be considered; and that
6 where appropriate, state and national experts in the
7 medical, psychological, ethical, social, and economic
8 effects or programs for the detection and management of
9 hereditary disorders *should* be consulted by the
10 department.

11 (c) Information on the operation of all programs on
12 hereditary disorders within the state, except for
13 confidential information obtained from participants in
14 the programs, *shall* be open and freely available to the
15 public.

16 (d) Clinical testing procedures *and protocols*
17 established for use in programs, facilities, and projects
18 *should* be accurate, *and* provide maximum information,
19 ~~and that the testing procedures selected~~ produce results
20 that are subject to minimum misinterpretation.

21 (e) No test or tests shall be performed on any minor
22 over the objection of the minor's parents or guardian, nor
23 may any tests be performed unless the parent or guardian
24 is fully informed of the purposes of testing for hereditary
25 disorders, and is given reasonable opportunity to object
26 to the testing.

27 (f) No testing, except initial screening for PKU and
28 other diseases that may be added to the newborn
29 screening program, shall require mandatory
30 participation, and no testing programs shall require
31 restriction of childbearing, and participation in a testing
32 program shall not be a prerequisite to eligibility for, or
33 receipt of, any other service or assistance from, or to
34 participate in, any other program, except where
35 necessary to determine eligibility for further programs of
36 diagnoses of or therapy for hereditary conditions.

37 (g) ~~Counseling~~ *Pre- and post-counseling* services for
38 hereditary disorders *shall* be available, through the
39 program or a referral source, for all persons determined
40 to be or who believe themselves to be at risk for a

1 hereditary disorder *when the belief arises* as a result of
2 screening programs; ~~the counseling is.~~ *Counseling shall*
3 *be provided by persons with appropriate training and*
4 *experience and shall be* nondirective, ~~emphasizes and~~
5 *emphasize* informing the client, ~~and not require~~
6 ~~restriction of childbearing.~~

7 (h) All participants in programs on hereditary
8 disorders be protected from undue physical and mental
9 harm, and except for initial screening for PKU and other
10 diseases that may be added to newborn screening
11 programs, be informed of the nature of risks involved in
12 participation in the programs, and those determined to
13 be affected with genetic disease be informed of the
14 nature, and where possible, the cost of available therapies
15 or maintenance programs, and be informed of the
16 possible benefits and risks associated with such therapies
17 and programs.

18 (i) All testing results and personal information
19 generated from hereditary disorders programs *shall* be
20 made available to an individual ~~over~~ 18 years of age *or*
21 *over*, or, *if under 18 years of age*, to the individual's parent
22 or guardian. If the individual is a minor or incompetent,
23 all testing results that have positively determined the
24 individual to either have, or be a carrier of, a heredity
25 disorder shall be given ~~through a physician or other~~
26 ~~source of health care to an appropriately trained health~~
27 *care professional.*

28 (j) All testing results and personal information from
29 hereditary disorders programs obtained from any
30 individual, or from specimens from any individual, *shall*
31 be held confidential and be considered a confidential
32 medical record except for ~~such~~ any information ~~as~~ *that*
33 the individual, parent, or guardian consents to be
34 released; provided that the individual is first fully
35 informed of the scope of the information requested to be
36 released, of all of the risks, benefits, and purposes for the
37 release, and of the identity of those to whom the
38 information will be released or made available, except for
39 statistical data compiled without reference to the identity
40 of any individual, and except for research purposes,

1 provided that pursuant to 45 Code of Federal Regulations
2 Section 46.101 et seq. entitled “Protection of Human
3 Subjects,” the research has first been reviewed and
4 approved by an institutional review board that certifies
5 the approval to the custodian of the information and
6 further certifies that in its judgment the information is of
7 such potentially substantial public health value that
8 modification of the requirement for legally effective
9 prior informed consent of the individual is ethically
10 justifiable.

11 (k) An individual whose confidentiality has been
12 breached as a result of any violation of ~~the provisions of~~
13 the Hereditary Disorders Act (Section 27) may recover
14 compensatory damages, and in addition, may recover
15 civil damages not to exceed ten thousand dollars
16 (\$10,000), reasonable attorney’s fees, and the costs of
17 litigation.

